

Considering a Seizure Alert Device

Steps to determine the best fit for you or your loved one

What are seizure alert devices?

A seizure alert device is a monitoring system that can detect when a person may be having a seizure and notify someone who can respond. Devices can be used by people of any age. Some systems also record and store seizure data that can be shared with your physician. Seizure alert devices do not prevent, diagnose or treat seizures or epilepsy. For information about these other types of devices, please go to www.epilepsy.com/devices or www.dannydid.org.

How do I know what type of seizure alert device I need?

A first step is to learn whether the device can detect the seizure type(s) you want to monitor. Different seizure types can be detected by different systems. It's important to remember that not all seizures can be detected by devices currently available, such as videos, watches, or mattress monitors. Talk to your neurologist or epilepsy specialist about your seizure type and what methods may work best for you. Also, think about the situations you are most concerned about. For example, are you more worried about nocturnal seizures when sleeping alone or having seizures during the day when out in public.



The next step is to ask yourself the following questions:

What do I want a seizure alert device to do?

Think about your main reason for wanting a seizure alert device.

- To notify someone when a seizure occurs by alarm, text message or phone call.
- To track and record how often seizures occur.
- To learn what your seizures look like.
- To have a safety check during or right after a seizure.
- To let someone know where you are if you are alone during a seizure.

What is my living situation?

Some devices work best if you live with someone else. Others can be helpful even if you live alone.

- Do you live alone or with someone?
- Do you have the resources to use the device and any technology that comes with it? For example, is Internet access required? Does it need a particular smartphone to work?
- Is someone able to respond and help you if they are alerted? If the person notified is in a different location, how would they check in with you?

Do I want to use the device outside the home?

Some devices are designed to work in one setting, such as inside the home. Other systems are mobile.

- Ask whether the device is GPS enabled and can show the users location.
- Find out if the device can alert an emergency medical responder (EMS)

What type of monitoring am I willing to use?

No device will be accurate if it is not used correctly. Ask yourself:

- Is the device physically comfortable to wear?
- Does the device make you stand out in a way that makes you uncomfortable?
- Does using the device raise concerns about your privacy?



Do I want the data from the device to be shared with other people?

Find out if the device allows you to share data and how this is done.

- Who do you want to see your data – family, health care provider, researchers? Can the device allow you to share this data with multiple people?
- Does the system share data in real-time or is it shared at a later date?
- What is done to protect my privacy when data is shared?

What is the cost?

- What is the cost of buying the device or is there a monthly or annual fee?
- Is the system covered by insurance? If yes, will the manufacturer submit it to insurance, or do you pay the full cost first, then get reimbursed?
- What is the product's return and refund policy? Is there a warranty program or help after a warranty ends?

What other factors should I consider?

- Are there weight or age restrictions to use it?
- If worn, does the device come in different sizes?
- Is it battery powered, or does it need to be connected to a power source? If it is battery powered, what is the battery life?



The Epilepsy Foundation and the Danny Did Foundation believe that optimal healthcare decisions are made when a patient and provider engage in honest, direct conversation. When possible, review what you've learned with your health care team.

This brochure was adapted with permission from the Child Neurology Foundation and the Danny Did Foundation.

CDC Disclaimer: This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting with their health care provider.

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Are there any downsides to using a device?

Before getting a seizure alert device, ask how reliable and sensitive it is in picking up the symptoms you want recorded.

- The device you select may not pick up all types of seizures that you have. In that scenario, an alert cannot be sent.
- How well does it detect the seizure types it is intended for?
- A device may pick up movements or events that are not seizures and you may get "false alerts." How are these false alerts handled? If there is a false detection, can you prevent an alert from being sent? Would this bother you or affect your decision about using the device?

Can the device prevent SUDEP or any of the factors that may lead to SUDEP?

- Seizure alert devices are not known to prevent sudden unexpected death in epilepsy (SUDEP). Yet by knowing when and how many seizures happen, you can talk to your health care team and learn about your risk for SUDEP.
- Devices may help you get first aid help sooner.
- We know that getting control of seizures is one of the most important ways of lowering a person's risk for SUDEP and other seizure emergencies.
- Collecting reliable data about your seizures may help you and your care team improve your seizure control.

Where can you get more information on seizure alert devices?

Think about:

- Talking to your health care provider – learn what's available and are most important for you.
- Calling the manufacturer for details about the system and its features.
- Reaching out to the Epilepsy Foundation 24/7 helpline (1-800-332-1000) or the Danny Did Foundation (info@dannydid.org) for more information.